

California Health Policy and Data Advisory Commission

**SENATE BILL 1109 REPORT
December 1996**

Improving Health Information for the Benefit of All Californians

STATE OF CALIFORNIA
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Preface

The primary goal of the State of California's health information program is to improve the health of all Californians.

This report focuses on recommendations made to the Office of Statewide Health Planning and Development (OSHPD) in order to achieve an effective health care data program; but, in a larger sense, the real audience of this report is all government agencies and departments involved in health care for the State of California. An irrefutable fact is that the State of California, in order to achieve its mandate to protect the health of its public, must have effective systems to collect and evaluate health care data. To build such systems requires a commitment to making access to accurate health care information fast, reliable, and useful. It requires taking advantage of the newest technologies available today and into the future. It requires broadening the focus of health care to include the expanding sites and sources of health care. It requires that the State of California have the flexibility to respond to a changing health care environment in order to use information in a way that ultimately improves the health of its people, and it requires that the State of California make an investment in systems that will achieve this goal.

The California Health Policy and Data Advisory Commission (CHPDAC) recognizes that the recommendations included here are ambitious both in scope and in time frame, but the time for boldness is now. The Commission strongly urges adoption and implementation of these recommendations in order to:

- Help California consumers make informed choices of health providers, plans and treatments.
- Assist health providers to improve quality of care.
- Help purchasers to better determine value.
- Enhance health professionals and researchers' efforts to advance evidence-based medicine.
- Assist policy makers to better safeguard the public's health.

No single entity is large enough to achieve these goals alone. Of necessity, many departments within the State Government must collect, use, share, and disseminate health data. Of equal necessity are more and better collaborative efforts both among State agencies and between the State and other public and private entities. An overall strategy is to achieve total on-line reporting so that all needed data are available to all appropriate users all of the time. Protection of individual privacy, appropriate data security, and confidentiality must be an integral component of the entire health information program.

The accompanying report is a wake-up call and a call to action. The time for commitment and action to enhance health and health care in California is here.

Introduction

This report summarizes the work of a distinguished committee of experts who were convened to evaluate and make recommendations for the future health information needs of Californians. Senate Bill 1109, sponsored by Senator Leslie and signed by Governor Wilson on October 4, 1995, directed the California Health Policy and Data Advisory Commission to establish this committee, subsequently named the California Health Information Committee (CHIC). Following public hearings that included testimony from over 40 private individuals and organizations, the CHIC then created two subcommittees to develop specific recommendations focusing on the State's future health information needs. The findings and recommendations of the subcommittees, although developed independently of each other, were remarkably similar and emphasized the importance of the changes outlined here. The Commission has produced this report, which endorses the CHIC's findings and recommendations, and is forwarding it to the Director of the Office of Statewide Health Planning and Development (OSHPD).

The goal of the CHIC was identification of a flexible way for the State of California to respond to a rapidly changing environment in order to improve the health of the public through health information. The Commission recognizes that the State requires flexibility to remove barriers to the speedy collection and distribution of useful information, and it requires flexibility in expanding its collection efforts to anticipate future demands. Just as importantly, the State must balance its information needs against the costs of collection by hospitals, long-term care facilities, health plans, clinics, and health professionals. The audience for health information includes consumers to improve choice; providers and health professionals to improve quality of care; purchasers to determine value; health professionals and researchers to enhance "best practices;" and policy makers to help safeguard the public's health.

A core set of principles underlies each of the recommendations in this report. These principles are:

- A well-educated public with access to appropriate health care is essential to the health of Californians.
- The dissemination of information should be appropriately based on the culture, language, race, gender, age, and geography of the target groups.
- The value of data collected by the State of California must be considered in relation to cost.
- The State Government is an entity with institutional stability that can provide publicly-available information that is reliable and verifiable with equal access to all, and that can provide objective analyses of outcomes of care, access to care, and patient satisfaction through collaborations among State agencies and in partnership with the private sector.

As illustrated by the last principle, an important finding of the CHIC was its recognition and re-affirmation of the role of the State. The State has responsibility to safeguard the health of its entire population. While the State has many roles including regulator, purchaser, and impartial arbiter, with respect to data the central State roles are:

- To collect data necessary to support the policy analyses and health assurance functions. In its data collection efforts, it is essential that archaic data be culled, that useful current data be maintained, and that the opportunity to enhance future data be assured.
- To undertake such analyses and research as necessary to make or recommend policy decisions on how to improve the health of the overall population and its subgroups.
- To use data to assure that public and private sector services efficiently and effectively contribute to improved health, and to take actions necessary to correct deficiencies.

Recommendations made by the CHIC encompass a broad and ambitious agenda that reflect these roles. The Commission has focused on five principal areas of the CHIC's recommendations. Two define primary objectives and the remaining three address operational issues. The areas are:

- **Timeliness, accuracy, and relevance:** To improve the timeliness, relevance, and quality of data currently collected.
- **Continuum of care:** To extend data collection across the continuum of care received by patients.
- **Technology:** To improve the speed and quality of information collection and distribution through improved technology.
- **Legislation:** To remove barriers to flexible information collection through legislative changes.
- **Funding:** To broaden the funding base for the collection and analysis of information.
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First Step Recommendations:

The five areas above encompass 16 specific recommendations. The Commission emphasizes that the recommendations contained here should be viewed in total rather than in isolation. Together, these recommendations outline a way to achieve the goal of improving the health of Californians through better and more useful information. Each individual recommendation is only part of a foundation that supports the entire structure of the State of California's health information system. Indeed, together these recommendations should be viewed as forming the beginning, rather than the completion, of that foundation.

Nonetheless, the Commission recognizes that the State of California is unique among the 50 states in the lack of statutory flexibility for data collection and many of the recommendations are contingent on eliminating these legislative barriers. Therefore, the Commission has singled out the following five recommendations as first steps:

Improving timeliness of the hospital patient discharge data: *The Commission recommends that as of January 1, 1998, the hospital patient discharge data should be submitted quarterly rather than semiannually, and all hospitals should submit the data in*

a computer-readable format. As of January 1, 1999, hospitals should incur penalties for inaccurate or unreadable submissions. Hospitals would have 90 days after the close of each quarter to submit the data, and OSHPD would have 75 days after submission to audit the data. By far, the most common comment received during public hearings was that the value of OSHPD's hospital discharge data to hospitals, researchers, purchasers, and consumers would be enhanced if these data were more timely. Currently, the public availability of these data lags a patient's discharge by up to 18 months. This recommended change will reduce that period to between six and nine months, and improved timeliness will benefit health care providers for their quality improvement purposes and consumers in their choice decisions.

Review of all existing financial and utilization databases: *The Commission recommends that OSHPD review all existing financial and utilization databases to evaluate the potential for combining, streamlining, or eliminating reporting requirements. OSHPD's financial and utilization databases were developed in an environment of cost-based reimbursement. Some portions of these reports may no longer accurately reflect the financial activities of hospitals. It is vital that there be accurate and relevant information on the financial status of health care systems and professionals. This recommended review will lead to efficiencies and cost-savings both for health care providers and for purchasers.*

Collection of new data: *Another comment received during public hearings was that the State of California should broaden its focus on health information from traditional inpatient hospital settings to include outpatient sites of care. Therefore, the Commission recommends that the State begin the important task of examining the continuum of care. As of January 1, 1998, OSHPD should collect data from emergency departments and ambulatory surgery settings. These data should be submitted in computer-readable formats. The Ambulatory Care Association has expressed an interest in working with OSHPD to develop an appropriate data collection tool. OSHPD should explore the use of electronic billing and encounter records (such as the Health Care Financing Administration's "HCFA 1500") as an initial source of data. Although billing records do not provide the depth of data provided, e.g., by OSHPD's Hospital Discharge Data Set, they cover far more patient encounters and would be a good way to begin collection of information from new sites of care. In collaboration with other public and private entities, OSHPD should continue to evaluate ways to collect information from additional sites along the continuum of care. Nonetheless, whether data are new or existing, OSHPD should fully utilize all State data bases and resources. Not only will this recommendation result in useful comparisons of performance and quality improvement in ambulatory surgery and emergency room settings, but also will allow the important tracking of care as it broadens from inpatient to outpatient care settings.*

Use of optimal technology: *The Commission recommends that OSHPD consult with outside experts for advice on the technology and computer resources that will most effectively address OSHPD's current and future needs. It should develop an implementation plan that recognizes both the departmental needs in terms of hardware, software and staff training, and the technological needs of the data users and suppliers. It should include an assessment of how to allow data suppliers to report only once and data*

users to access that data as needed and permitted. In order to be most useful, OSHPD should evaluate the quality of information as it is received and produce a public report on the quality of submitted data. This recommendation addresses the need for efficiencies that will lead to cost savings for health care providers and the State, and improved timeliness so that both can keep up with market trends to help consumers and purchasers with choice and providers for value and quality improvement.

Establishment of oversight entity and extension of sunset: *The Commission recommends that the State develop broad, flexible statutory language authorizing data collection, data standards, outcome measurements, data linkages, and other health care studies.* Legislation should define a process that balances the need for flexibility with the need for full statutory control. It must define areas of change that will not require legislative or regulatory amendment. One approach would be to identify an oversight entity, such as the Commission, through legislation to monitor, advise, and facilitate data collection policy and procedural changes over time. This entity would have a broad representative membership including representatives from providers, purchasers, the public, government, researchers, and health professionals. *The Commission also recommends that the sunset date for OSHPD's Health Data programs should be extended to January 1, 2004, so that the important objective of providing information to improve the health of Californians can be implemented.* The recommended five year extension should not be viewed by OSHPD as a routine extension for the preservation of the status quo, but rather as an opportunity to move forward and develop new and more effective ways to collect and share health information. This recommendation addresses the need for OSHPD to achieve flexibility to meet consumer, purchaser, and provider needs in a rapidly changing health care environment.

These five recommendations, included with the full set of recommendations that follow, identify the beginning of a path OSHPD must follow to reach the ultimate goal of providing information to improve health care. To ensure that this objective is met, it is imperative that OSHPD develop a work plan that addresses each of the following questions:

- What specific actions need to be taken to implement each recommendation?
- What participants or potential partnerships may be involved?
- What incentives will each participant need?
- What new data, if any, are required?
- What costs will be incurred by the State, by other public entities, and by private organizations?
- What criteria will be used to evaluate how well each recommendation achieves its objective?

The Commission recognizes that the task facing OSHPD is considerable. It is, therefore, essential that OSHPD's progress on each recommendation should be monitored through quarterly reports to the Commission beginning in April 1997.

Summary Of Recommendations

(* Denotes a first step recommendation)

Timeliness, Accuracy, and Relevance

- 1.* Reduce the time allotted for the collection and reporting cycles for OSHPD databases.
2. Explore opportunities to develop OSHPD's role as health information clearinghouse to serve as a single point of access for health care information.
- 3.* Review all existing financial and utilization databases to evaluate the potential for combining, streamlining, or eliminating report requirements.
4. Provide publicly-available research that addresses health care quality, costs, and access, and facilitates the development of public policy that anticipates and responds to market changes.
5. Develop opportunities for public/private partnerships.
6. Track financial viability, financial incentives, community benefits and organizational structure of delivery systems.

Continuum of Care

- 7.* Collect data from emergency departments and ambulatory surgery settings.
8. Collect data that track the full continuum of care.
9. Examine and understand the continuum of care and health needs for communities.
10. Track the rate of avoidable hospitalizations or ambulatory care sensitive conditions.
11. Track information with universal identifiers.

Technology

- 12.* Develop an implementation plan that enables OSHPD to use optimal technology for its data collection, processing, linkage, and dissemination functions.
13. Enhance use of existing standard measures and definitions without compromising the quality of the data collected.
14. Support and promote national standards for confidentiality, security, and privacy for data collection and dissemination.

Legislation

- 15.* Develop broad, flexible statutory language authorizing data collection, data standards, outcome measurements, data linkages and other health care studies, and extend the OSHPD data program sunset date to 2004.

Funding

16. As part of the State's role in tracking care across all sites and professionals, OSHPD should broaden its funding sources.

RECOMMENDATIONS

Timeliness, Accuracy, and Relevance

During public hearings, the CHIC heard that the data currently collected by OSHPD would be of greater value if they could be made available more quickly. However, the timely availability of data is unimportant if those data are inaccurate or not useful. The following recommendations focus on improving the usefulness of OSHPD's databases by culling data elements that are no longer useful, expanding reporting to include data needed for the future, ensuring the accuracy of data collected, and reducing the time before those data are publicly available.

1. Reduce the time allotted for the collection and reporting cycles for OSHPD databases. (A first step recommendation)

There is a great demand for more current patient discharge data. The Commission recommends that as of January 1, 1998, the hospital discharge data should be submitted quarterly rather than semiannually, and all hospitals should submit the data in a computer-readable format. The goal is that as soon as feasible thereafter, the data should be submitted completely electronically (i.e., in an "on-line" fashion). Hospitals would have 90 days after the close of each quarter to submit the data and OSHPD would have 75 days after submission to audit the data. Currently, hospitals are fined for late data submissions. Since even on-time data submissions are undermined if data quality is poor, as of January 1, 1999, hospitals should incur penalties for inaccurate or unreadable submissions.

In addition, other OSHPD databases should be reviewed to enhance the timeliness of collection and reporting. This would require: (1) identifying the relative value of timeliness vs. accuracy for major data users; (2) identifying those processes and elements that may impede timeliness while adding only marginal value; and, (3) evaluating more appropriate reporting cycles for each database as the use of technology increases.

2. Explore opportunities to develop OSHPD's role as health information clearinghouse to serve as a single point of access for health care information.

OSHPD should facilitate a better understanding of the rapidly changing health care environment by identifying existing resources that may be useful to the public. Examples may include information on health plans and provider groups such as from the California Cooperative HEDIS Reporting Initiative, and ways to achieve healthy living,

guidance on how to purchase medical care, and how to make important health decisions. After identifying resources, creating a guide to resources will allow Californians to obtain this information more easily. It could include information that covers the course of life and the continuum of care. OSHPD can explore innovative ways to develop processes and tools to assess whether the data are valid and verifiable; seek useful data that are not available; identify who will benefit from using the information; and make this information available to the public through the most effective points of dissemination.

Information can also be distributed more efficiently by expanding the capabilities of an existing OSHPD group, such as the Data Users Support Group. This group can be a more valuable resource through increased training and an augmentation of computer resources. It is also an ideal site for a reference library that may be created by tracking user requests and actively seeking research reports based on OSHPD data.

Dissemination of information to the public based on a compilation and evaluation of existing information has the advantage of addressing the immediate needs and interests of the public without requiring new data collection.

3. Review all existing financial and utilization databases to evaluate the potential for combining, streamlining, or eliminating reporting requirements. (A first step recommendation)

OSHPD's financial and utilization databases were developed in an environment of cost-based reimbursement. Some portions of these reports may no longer accurately reflect the financial activities of hospitals. It is vital that there be accurate and relevant information on the financial status of health care systems and professionals.

Consequently, OSHPD should contract with one or more accounting firms with experience in the health care industry to assist in the review of the financial reporting system to identify ways to combine, streamline, or eliminate some of the reporting requirements. The review process should be sensitive to the data needs of major users, including entities such as the hospitals, the Department of Health Services, the Department of Justice, private consultants, and accounting firms.

4. Provide publicly-available research that addresses health care quality, cost, and access, and facilitates the development of public policy that anticipates and responds to market changes.

OSHPD currently strives to conduct research that is useful to the public, purchasers, and providers to ensure the health of Californians. The State Government is an entity with institutional stability that can provide publicly available information that is reliable and verifiable with equal access to all, and it can provide objective analyses of outcomes of care, access to care, and patient satisfaction. The State has a role as purchaser and as a protector of public health to participate in a research agenda, preferably through

partnerships. A special effort should be made to share this research with schools of health professionals so that they can balance the production of professionals with community needs.

5. Develop opportunities for public/private partnerships.

Providing relevant, non-duplicative information may be enhanced by engaging in partnerships both among State agencies and with private entities. While the State should always have a role in monitoring the quality of health care provided to all Californians, its resources are limited and it should attempt to foster research by forming public/private partnerships whenever appropriate. For example, partnerships may include purchaser coalitions, universities, health plans, private research organizations or other State agencies. These organizations often offer not only material resources, but intellectual resources that have the potential to make the work more applicable and relevant. Opportunities for partnerships exist now and should be investigated as a way to achieve these objectives.

OSHPD has the opportunity to develop more effective working relationships with other organizations to evaluate and monitor quality. OSHPD and other Health and Welfare Agency departments should also recognize, support, and promote policy recommendations set forth in focused national efforts to address the need to improve health data laws, policies, and practices used by health data organizations. Such efforts serve to address new trends, issues, and advances in technology.

6. Track financial viability, financial incentives, community benefits and organizational structure of delivery systems.

An understanding of the current and future financial viability of health care institutions, medical groups, and integrated delivery systems will provide the State and the public with a better ability to determine the stability of the health care system and the potential effect if institutions close or leave a community. It will also provide information on issues related to antitrust and the obligations of not-for-profit entities that may be involved with for-profit entities.

While health care systems are changing rapidly, OSHPD can begin by gathering more information on the organizational structure of health care systems, which is not currently available. This may be supplemented by core financial data that could be collected at the corporate level. For example, these data could be extracted from reports currently filed with the Department of Corporations. Data could be collated, organized, and shared with the source organizations so they can “benchmark” their performance against others.

Continuum of Care

An estimated 60 percent of surgeries are now being performed on an outpatient basis. “Ambulatory care” is a growing component of the system and includes medical care in

physician offices and clinic settings, work sites, retirement communities, home care, skilled nursing facilities, and alternate settings. More health plans are also evaluating and providing reimbursement for alternative types of health care, so only examining conventional therapies within a hospital system provides an inadequate picture of health care. Data should be used in a way to evaluate the health of all Californians, not just the health of those who use conventional health services, or those who have an ability to pay. For all of these reasons, there is a need to establish measures of health that extend across the continuum of care of individuals.

7. Collect data from emergency departments and ambulatory surgery settings.

(A first step recommendation)

The State can begin the important task of examining continuum of care by designing an implementation plan to collect data from emergency departments and ambulatory surgery settings. These data should be collected in computer-readable formats as of January 1, 1998. The Ambulatory Care Association has expressed an interest in working with the State to develop an appropriate data collection tool. The State should explore the use of electronic billing of encounter records (such as the HCFA 1500 as an initial source of data). Although billing records do not provide the depth of data provided by, for example, OSHPD's Hospital Discharge Data Set, they cover far more patient encounters and would be a good way to begin collection of data from new sites of care.

8. Collect data that track the full continuum of care.

OSHPD should develop and implement a plan to collect encounter level patient data reflecting the continuum of care, to establish collaborative relationships with DHS, HCFA, and others to obtain encounter level data, and to promote opportunities to collect encounter level data from other settings along the continuum of care. The increasing emphasis on pharmaceuticals as a less expensive treatment protocol creates a need for information from pharmacies and pharmacy benefit management companies.

As the State addresses issues of continuum of care, it is important for OSHPD to coordinate with other state and federal agencies, and private entities to assure the capacity to systematically collect population-based survey data, especially to address risk-factor assessment and the needs of vulnerable populations such as children, the elderly, the chronically ill, and the developmentally disabled.

As a long-term objective, the State should take steps to measure access, utilization, cost, and the quality of complementary care (such as acupuncture and chiropractic) and supplementary care (such as physical or speech therapy), both of which are acquiring increased acceptance. Data should be collected about training, quality, costs, and outcomes of therapies. This could be initiated by focusing on several widely used types

of complementary care. Community and public surveys may be an important approach to this complex and understudied area.

9. Examine and understand the continuum of care and health needs for communities.

OSHPD should use the community benefits legislation (Senate Bill 697, or Chapter 812 of the Statutes of 1994), as a framework for acquiring better information on individual communities, establishing objective measurable standards and obtaining comparable data over time on the community benefits provided by not-for-profit hospitals and integrated delivery systems. The State has initiated efforts, through SB 697, to understand the integrated efforts of not-for-profit hospitals and other health care organizations to address the health needs of communities.

OSHPD should supplement and enhance work related to SB 697 by identifying data currently available to measure population health and functional status. “Functional status” includes psychosocial factors, activities of daily living, and quality of life measures. Since health status is influenced by genetics, environment, nutrition and other circumstances, any examination of the factors affecting the health of individuals is limited if the focus is only on medical care. National health surveys and other data sets (e.g., SF-36 surveys, data from the National Institutes of Health, or from the National Center for Health Statistics) have the potential to offer information on California communities to enhance community health profiles and should be explored. OSHPD should explore ways for health plans, public health authorities and others responsible for the health of communities to become more involved in the collection of these data for the groups for which they are responsible, not just their patients. OSHPD should facilitate this involvement by creating mechanisms to share information about quality including outcomes or other measures related to specific communities with community organizations and to share information about quality with schools for health professionals so that training and supply can meet needs.

The legislation for reporting community benefits by not-for-profit hospitals represents a first step, but OSHPD, who must make recommendations to the Legislature regarding SB 697, should make a commitment to maximizing the benefit and usefulness of this legislation to increase understanding of the health needs of California communities.

10. Track the rate of avoidable hospitalizations or ambulatory care sensitive conditions.

Hospitalizations for conditions that can often be effectively treated on an outpatient basis, referred to as ambulatory care sensitive (ACS) conditions, may indicate poor access to primary care resources. Examining ACS conditions by area and by payer is the first step to identify what health care resources need to be available and where access to earlier intervention needs to be improved for specific areas or groups. There is

valuable research in this area, and OSHPD should pursue partnerships with other researchers, in both the public and private sectors, interested in these issues.

11. Track information with universal identifiers.

It is essential, in order to measure quality across sites of care, that the State adopt a way to link patient records across time and sites of care. To understand what types of health professionals are treating specific patients and illnesses and how this may be changing, it is important to have unique identifiers for both patients and various types of health professionals. Thus, the State should adopt a unique patient identifier consistent with federal initiatives that would protect the patient's privacy but would still allow for record linkage across databases and State boundaries. The State should also study the potential value of collecting the Unique Physician/Practitioner Identification Number (UPIN) currently used by HCFA for Medicare, and consider endorsing efforts to develop UPIN for non-physician health professionals.

Technology

These significant changes that have taken place in both the health care industry and in electronic information technologies have opened up new opportunities for OSHPD to optimize use of technology in providing timely and accurate information. It is crucial that the State invest in technology to carry out its functions.

12. Develop an implementation plan that enables OSHPD to use optimal technology for its data collection, processing, linkage, and dissemination functions. (A first step recommendation)

OSHPD should consult with outside experts for advice on the technology and computer resources that will most effectively address OSHPD's current and future needs. OSHPD should develop an implementation plan that recognizes both the departmental needs in terms of hardware, software and staff training and the technological needs of the data users and suppliers. Plan development would require cooperation with other departments of the State to establish technology standards in order to enhance future flexibility in coordination of data collection. It should include an assessment of how to use technology effectively to allow data suppliers to report only once and data users to access that data as needed and permitted.

OSHPD should identify ways to distribute existing data (such as through "web sites," file transfer protocol (ftp), and CD-ROMs), both in raw and in standardized formats commonly used by researchers, in ways that will speed access to and use of the data. An important way to speed access is to distribute information as soon as it is received, clearly marked as being "as submitted and subject to change." In order to be most

useful, OSHPD should track and evaluate the quality of information as it is received, and produce a public report on the quality of submitted data.

In the near term (one-two years) OSHPD should coordinate and consolidate inconsistent and parallel processes and definitions that currently exist across its databases. OSHPD should identify the most effective way to move toward standardized, electronic encounter- level reporting of patient services (such as “electronic medical records” or “computer-based patient records”) that will not compromise the quality of current patient level data and will allow for increased flexibility of reporting in the future.

OSHPD should develop or adopt standard data elements to enable linkage of databases, including patient level and facility based data. This may be achieved by supporting both the permanent status of the California Health Information for Policy Project (CHIPP) in California’s health data collection and dissemination structure and CHIPP’s pilot projects in database linkage.

OSHPD and other State agencies should coordinate with private and non-profit entities in the development of a statewide health information infrastructure to improve quality of care and health care efficiency.

13. Enhance use of existing standard measures and definitions without compromising the quality of the data collected.

OSHPD should actively participate in national efforts to set and maintain meaningful standards for health care data definitions and transmission. As part of this effort, OSHPD can establish a structure to assure continuation of data standardization efforts within OSHPD and the Health and Welfare Agency.

14. Support and promote national standards for confidentiality, security, and privacy for data collection and dissemination.

OSHPD should update current confidentiality policy to accommodate expanded issues of data integration and linkage. The Commission recommends formation or designation of an administrative body within the Health and Welfare Agency to promulgate privacy and confidentiality policies on data dissemination and to coordinate active communication and collaboration with other government and private organizations so consistent policies relevant to State and federal law can be formulated. The administrative body’s activities would include separately defining issues of confidentiality, security, and privacy, and reviewing the extensive work already done by others, nationally and internationally.

Comprehensive programs to educate and train employees should be developed. To promote and secure public trust, OSHPD should state its commitment to assure privacy and confidentiality in all its data and publications.

Legislation

California faces uniquely inhibiting restrictions to data collection imposed by statutory inflexibility. Current authorizing legislation specifically lists individual data elements and their definitions, data collection and reporting deadlines, detailed research parameters, and the schedule of results for outcome studies. Such detailed legislative mandates inhibit the flexibility of the State's information collection and reporting systems to continue to reflect the rapidly changing health care delivery system.

15. Develop broad, flexible statutory language authorizing data collection, data standards, outcome measurements, data linkages and other health care studies. (A first step recommendation)

Legislation should define a process that balances the need for flexibility to respond to change with the need for full statutory control. It should define areas of change that will not require legislative or regulatory amendment. One approach would be to identify an oversight entity, such as the Commission, through legislation to monitor, advise, and facilitate data collection policy and procedural changes over time. This entity would have a broad, representative membership including representatives from providers, purchasers, the public, government, researchers, and health professionals.

The State should support and promote federal legislative efforts to establish a uniform requirement for the assurance of confidentiality and protection of privacy rights for personal data that ensures a balance among required disclosure, use of data, and patient privacy. Such legislation should establish penalties, provide for enforcement, and define compliance.

The Commission also recommends that the sunset date for OSHPD's health data programs should be extended to 2004 so that the important objective of providing information to improve the health of Californians can be implemented.

Funding

16. As part of the State's responsibility in tracking the continuum of care across all sites and professionals, OSHPD should broaden its funding sources.

Currently, hospitals contribute a large share of OSHPD's funding. Legislation should establish appropriate funding mechanisms that would include other organizations to cover the costs of collection and dissemination of information by the entities that are providing health information.

